

What to tell patients' families to expect when a loved one is dying

Written by Dr. John Crosby on May 27, 2014 for CanadianHealthcareNetwork.ca

Some helpful tips I've developed to provide comfort for caregivers of dying patients

Canadians rarely see dying and death. This is because it often happens in the hospital and is somewhat hidden away. Loved ones are often in denial and are afraid to ask about the specifics of the dying process.

The following is a useful handout that I give out to all the staff, family and friends of dying patients at home or in the nursing home. I ask them to read it carefully.

Although it is impossible to totally prepare for a death, it may be made easier if you know what to expect. Death is a natural process as the body begins shutting down. The following physical and emotional signs of approaching death are described to help you understand what can happen.

**Please note: each person is unique. This advice is intended only as a guide and may help provide comfort to the dying person and their loved ones. It is not intended to replace advice given by a healthcare professional.*

Helpful hints

Sit with the dying person; hold their hand. Reassure the person and remind them you are there. Do not speak about them as though they are not present. Hearing remains until the moment of death.

Identify yourself by name. Speak softly, clearly and truthfully when you need to communicate something important. Talk to the person while giving care, telling them what you will be doing.

A calming effect may be achieved by sitting quietly at the bedside, playing soothing music or reading something comforting. A light blanket might provide comfort to someone with cool skin.

Goodbyes are appropriate. Both the family and the person dying may find comfort in this process of "letting go."

During this time a member of the clergy or a spiritual adviser can provide support and comfort to both the family and the person dying. Certain religions have rites and sacraments that may be desired. It is wise to arrange for the clergy or spiritual adviser to be on call if required.

It is helpful if you and your family discuss funeral plans before death. This will avoid having to make major decisions at a very stressful time.

Normal family routines may be disrupted and you may feel you have lost the ability to concentrate on anything. You may sometimes wish for things to be over because of the uncertainty, helplessness and emotional and physical exhaustion you may be experiencing.

Feelings such as guilt, anger, frustration or sadness are common among people who are supporting a person dying. These are common feelings and a normal response. And tears are a natural expression of one's feelings.

Physical signs of approaching death

Food and fluid: Loss of appetite and decrease in thirst are common. The body is beginning to shut down and does not need nourishment. People commonly feel it is necessary to encourage the person to eat in the hope of sustaining life; however food and fluid may cause discomfort. The person may ask for ice chips, popsicles, ice cream or some other food choice. Do not be surprised if only a mouthful is taken. When swallowing is no longer possible, mouth care provides moisture and comfort. Do not give fluids if unable to swallow, as they may go down into the lungs and cause distress, pneumonia or chest infection.

Pain and anxiety: These issues can be controlled by medications prescribed by the doctor.

Elimination: Urine output and bowel function will decrease as the food and fluid intake decreases. Urine and stool may also change colour, be passed less frequently and in smaller amounts. Other factors such as immobility and medication may contribute to this.

The person may lose control of bladder and bowel function as the muscles begin to relax. In this instance it may be necessary to use an incontinence brief.

It is important to provide skin care and cleansing on a routine basis. Nursing services may be available to help you through home care. Ask your family doctor's staff.

Sleeping: Sleeping an increased amount is common. It may become more difficult to wake the patient. As death nears, the person may slip into a coma and become unresponsive.

Restlessness and distortion: Confusion as to time, place and recognition of people is common. This can include members of the family and close friends. At times the person may become restless. For example, she/he may reach out to unseen objects, pull at the bedclothes or try to get out of bed. This can occur for many reasons such as a decrease in oxygen circulation to the brain or medication side effects.

Breathing: Regular breathing patterns may change. Breathing may become noisy due to mucous collecting in the throat. You may notice shallow breath with periods of no breathing. These breathing patterns are normal and indicate the natural progression towards death.

Congestion: Gurgling sounds occur when a person is unable to cough up normal secretions. This does not normally cause any pain or discomfort. It may be helpful to turn the person to one side and gently wipe away secretions with a moist cloth. As secretions build up, keeping the head of the bed elevated (pillows may be used) will make breathing easier. Sometimes a medication can be ordered by the doctor to help dry up secretions.

Skin: You may notice the skin begin to change colour and be cooler to the touch.

How will you know when the patient is dead?

It is impossible for anyone to predict time of death. When it occurs, there will be no response and there will be no breathing. There will be no pulse in the neck.

Do not call 911. This is an expected death.

Call your family doctor or the doctor who has been doing palliative care and ask for the family doctor on call who will travel to where you are to pronounce death and sign a death certificate. You can then call the funeral home to remove the body. Take medications back to the pharmacy for safe disposal.

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